RISK: Health, Safety & Environment (1990-2002)

Volume 12
Number 1 *Issue number 1/2, Spring 2001*

Article 15

March 2001

Review of: The Human Genome Project and Minority Communities - Ethical, Social, and Political Dilemmas (Raymond A. Zilinskas & Peter J. Balint eds.)

Craig Steven Jepson

Review of: The Human Genome Project and Minority Communities - Ethical, Social, and Political Dilemmas (Raymond A. Zilinskas & Peter J. Balint eds.)

Erratum
The citation for this review is *12 RISK* 143 (2001) in most commercial databases.

The Human Genome Project and Minority Communities — Ethical, Social, and Political Dilemmas (Raymond A. Zilinskas & Peter J. Balint eds., Praeger Publishers 2001). Preface, index, about the contributors. LC 00-032390; ISBN 0-275-96961-4 [160 pp. $54.50. Cloth, 88 Post Road West, Westport, CT 06881].

This short, well-edited, collection of essays reflects and grew out of the proceedings of the conference, "The Human Genome Project: Reaching the Minority Communities in Maryland," held at the University of Maryland in the summer of 1997. The editors' stated objectives include: (1) building bridges between human genetics researchers and the minority community in Maryland; (2) presenting an introduction to the Human Genome Project (hereinafter HGP); and (3) airing legal, ethical and social concerns the authors believe are raised by the information produced through human genetics research. In Chapter 11, the editors elaborate on their agenda in their own contribution to the collection, "The HGP and Minority Communities: The Importance of Dialogue and Access to Information."[1] This provocative collection is for social scholars and students, and in particular, community leaders involved with minority and public health issues.

The editors argue that the distrust, skepticism and misconceptions of minorities relating to genetics research must be overcome. Yet, the editors report that the participants left the conference more apprehensive than when they came. Scientifically unsophisticated readers of the book will fare no better. Reference, often without dates, is five times made to the Tuskegee syphilis experiment of forty years ago. Negative reference is made innumerable times to misuse of genetic information, discredited twin studies, eugenics, and to Hernstein and

1 First editor Raymond A. Zilinskas, Ph.D, is a Senior Scientist at the Center for Nonproliferation Studies, Monterey Institute of International Studies in Monterey, CA, where he studies effective biological arms control. He is editor of *Biological Warfare: Modern Offense and Defense* (Lynne Rienner Publishers, 1999). His doctoral dissertation at the University of Southern California addressed policy and ethical issues generated by DNA research. Co-editor Peter J. Balint is an Adjunct Lecturer in Quantitative Methods at the University of Maryland, where he is a Ph.D. candidate in environmental policy at the School of Public Affairs.

Murray's controversial 1994 book **The Bell Curve.** Indeed, the index lists nine separate entries for **The Bell Curve.** While the editors can perhaps be forgiven for ignoring, in a collection aimed at social scientists, the solid research supportive of biological determinism and the benevolent uses of genetic information, the treatment comes off one-sided.

To their credit, however, the editors and contributors acknowledge that the HGP is conducted in accordance with the highest ethical standards, and has the potential to make dramatic positive contributions to the health of all human beings. Several contributors explore the notion that members of minority communities in particular — who statistically are at high risk -— have much to gain from innovative medical diagnostics and therapies that will result from the study of human genetics.

The editors also report failure in their goal of interesting the government and private foundations in involving minority communities at the state-level in redistributing the benefits of genetic research and the HGP, to ensure that those benefits are "shared equitably." The editors do not adequately elaborate on this intriguing thesis. They do, however, express a generalized fear that the benefits of the HGP will disproportionately accrue to the privileged and a generalized concern that the information produced will be beneficial primarily to Caucasians.

For example, in Chapter 4, "The Human Genome Project and the African American Community: Race, Diversity, and American Science," noted University of Maryland scholar Fatima Jackson sheds some light on the unstated proposal. Those familiar with a famous 1990 case from the California Supreme Court will be familiar with the context of Henrietta Lacks' story. The California legal system allowed the University of California to benefit financially from the unconsented-to use of spleen cells taken from cancer patient John Moore. The University of California was not required to share any financial bounties with Mr. Moore. Likewise, Ms. Lacks, an African-American resident of Maryland, never received financial compensation,

or credit, for the scientific and medical benefits that resulted when her cells were used without her consent by Johns Hopkins University. When Ms. Lacks was a patient at Johns Hopkins in 1951, doctors took her cells and used them as the basis for the extremely valuable HeLa cell typing system. Jackson purports that there has not been financial compensation or credit for this important scientific contribution.

Lastly, the editors report failure in their effort to promote interaction between scientists who perform HGP research and leaders of the minority community. The editors write of their disappointment, or perhaps surprise, that while administrators and managers at leading research institutions promised to encourage working scientists to participate in the conference, none of the bench scientists participated as the editors desired. The scientists doing cutting-edge genetics research were willing to address the conference, but not to participate as resource persons.

Nonetheless, Zilinskas and Balint remain optimistic and argue that the HGP has the potential to make dramatic positive contributions to the health of all human beings. They stress that members of minority communities have much to gain from innovative medical diagnostics and therapies that will result from the study of human genetics. This book, they hope, will serve as both the media and the message for the important task of bridging the gap between the scientific and minority communities.

Craig Steven Jepson†

---

† Mr. Jepson is a Professor of Law at the Franklin Pierce Law Center, Of Counsel with Verrill & Dana LLP, Portland, Maine, and a consultant to the Food Research and Development Institute of the government of Taiwan. Mr. Jepson teaches Biotechnology Law at FPLC and the University of Maine.

Join the Risk Assessment & Policy Association

On the web, see http://www.fplc.edu/risk/rapa.htm.

The March 2001 Biennial International Conference has been postponed until 2002.

Future Biennial International Conferences will be on a schedule for even-numbered years.

In the interim, the RAPA officers are exploring the possibility of sponsoring a one-day symposium in Washington, D.C. later this year (with the possibility of sponsoring similar symposiums on a biennial schedule of odd-numbered years).